

4 TREATMENT OPTIONS

Visit www.LLS.org/CaregiverWorkbook to access all chapters and worksheets.

Learning About Treatment Options. After your loved one is diagnosed with a blood cancer, they will work with members of the healthcare team to determine the best treatment plan. Treatment options vary for the different types of blood cancer. Your loved one's treatment options depend on their specific diagnosis, age, cytogenetic analysis (an examination of the chromosomes in the bone marrow, blood and lymph node cells), overall health and other factors.

The patient's treatment plan might include:

- The watch-and-wait approach
- Chemotherapy
- Targeted therapy
- Radiation therapy
- Immunotherapy
- Stem cell transplantation
- Clinical trials
- Blood transfusion
- Palliative (supportive) care
- A combination of any of the above

Surgery can be, but usually isn't, a part of treatment for cancers that involve the blood and marrow. Drug therapies can be given in a few different ways. See **Methods To Administer Drugs** on page 9.



Once the treatment plan is decided, note the details in **Your Loved One's Treatment Plan** on page 12.

Generic and Biosimilar Drugs. Your loved one's treatment plan may include the use of generic or biosimilar drugs. Both generic and biosimilar drugs are approved by the United States Food and Drug Administration (FDA) and may offer a more affordable treatment option for patients.

How Generics Are Made. A generic drug is the same as a brand-name drug in dosage, safety, strength, how it is taken, quality, performance, and intended use. Before approving a generic drug product, the FDA requires many rigorous tests and procedures to assure that the generic drug can be substituted for the brand-name drug.

How Biosimilars Are Made. Many drugs developed are called "biological products" (known as "biologics", also known as "the reference product") because they are produced through biotechnology and use living systems, such as a microorganism or a plant cell. Monoclonal antibodies and vaccines are some examples of biological products. Because

FACT

"Palliative care" is not just end-of-life care. Palliative (supportive) care can also be used, alongside curative treatment, to help manage side effects and improve the patient's well-being.

TIP:

Pack a tote bag with items to make waiting rooms and treatment days more bearable. Bring a book, tablet, magazine, puzzle book, a music player and headphones, or a journal and pen to entertain yourself and your loved one. Pack a sweater or blanket since treatment centers can be chilly. Add snacks and a water bottle. And, don't forget a phone charger!

the makeup of biologics is very complex, it is challenging to create imitations of the drug. Generic drug development is simple, like following a recipe with standard ingredients. Biosimilars are more challenging because they are made up of living cells, which are very sensitive to their environments and cannot be recreated by a chemical formula. Manufacturers have to create their own, unique process to create an identical outcome to an existing treatment.

Biosimilars:

- Are imitations of biologics (the FDA-approved reference product)
- Are highly similar to their reference products—this means that the product is analyzed using technology that compares the characteristics of the reference product and the biosimilar.
- Have no meaningful differences from the biologics—this means that the manufacturer of the biosimilar has shown that there are no differences between the reference product and the biosimilar in terms of safety, purity and potency (safety and effectiveness). This is shown by putting the biosimilar through human clinical trials.



Visit www.LLS.org/biosimilars to learn more about generic and biosimilar drugs.

Helping Your Loved One Choose a Treatment Plan. Your loved one may ask you to participate in the process for choosing a treatment plan. You can help in some of the following ways:

- Research and collect information on the patient’s diagnosis and suggested treatment options.
- Be the patient’s second set of ears or offer to take notes at appointments.
- Help the patient find a blood cancer specialist for a second opinion to confirm the treatment plan.
- Help the patient keep a running list of questions to ask members of the healthcare team.
- Be a sounding board for the patient to discuss each treatment option.

Remember, ultimately, treatment decisions are up to the patient. In an open discussion, you can share your perspective with the patient. Be respectful and supportive of the patient’s decisions, even if you disagree with the choices they are making.

Researching Treatment Options. Caregivers often become the primary “researchers” for disease information and support in an effort to assist the person with cancer and to help them better understand the disease, treatment options and side effects. Be wary of information found online. Always check to make sure the information is provided by a reliable source.



LLS offers free materials and services designed to simplify this search for information and support. Visit www.LLS.org/InformationSpecialists or call **(800) 955-4572**.



Visit www.LLS.org/treatment to learn more about specific treatments.

Watch and Wait. The watch-and-wait approach involves closely monitoring a patient’s condition without starting any active treatment until disease characteristics, signs and/or symptoms either appear or change. Some people, with their doctor’s care and guidance, can manage their blood cancer—depending on the disease—for years using a watch-and-wait approach. This approach is usually recommended for patients who are in the early stages of indolent (slow-growing) disease or some chronic forms of blood cancers.

As part of the watch-and-wait protocol, the doctor will monitor the patient’s condition for disease progression with regular physical examinations and lab tests. The patient won’t take any drugs or undergo any forms of active treatment for the blood cancer diagnosis during this period. (The patient may be on medications for other medical conditions.)

The patient can avoid drug treatment and its potential side effects until it is needed. The watch-and-wait approach is based on study findings indicating that early treatment for some patients, in some situations, isn't beneficial.

Patients following the watch-and-wait protocol must visit the doctor regularly so the doctor can check for any changes in their health. The doctor will specifically monitor the patient's disease status and whether the disease is stable or starting to progress. The doctor looks at the patient's test results to decide when it is time to start treatment and to determine the best treatment option. Depending on the disease, the doctor may advise the patient to begin treatment if the patient has:

- Lymph nodes that are getting larger
- Newly affected lymph nodes
- Bone or other organs that have become affected by cancer
- A low blood cell count
- A relatively rapid increase in the number of lymphocytes in the blood
- A spleen that's increasing in size
- Worsening anemia
- Pain

Caregiver Responsibilities During Watch and Wait. You may feel uncomfortable because you know that your loved one has cancer, yet they are not receiving treatment right away. Your loved one may also feel uncomfortable about not starting treatment right away. Rest assured that the watch-and-wait approach is the standard of care for people whose disease is not progressing quickly, is not widespread and who have no signs and/or symptoms.

Your caregiver responsibilities during this time may be limited to accompanying your loved one to checkups and providing emotional support. During the watch-and-wait time period, it's very important for your loved one to follow up with the healthcare team as instructed, even if they feel fine. Encourage your loved one to maintain the appropriate follow-up schedule. Ask how you may be able to help, for example, scheduling appointments for them or sending reminders for upcoming appointments. You can also help them to watch for new signs and/or symptoms and make sure that they are reported to the healthcare team right away.

Ask your loved one if they are comfortable sharing the diagnosis with others during watch and wait. Some patients are less comfortable sharing their diagnosis if they will not be receiving treatment in the immediate future.

Chemotherapy. Chemotherapy (chemo) is the use of strong drugs or chemicals, often given in combinations or administered at intervals, to kill or damage cancer cells. Chemotherapy drugs are often called "anticancer agents." Chemotherapy can produce long-term remission (no sign of illness) or outright cure for many people, depending on the type of cancer and its stage.

Not all chemotherapy treatments are the same. Certain chemotherapy drugs are used only for certain disease types. All chemotherapy drugs interfere with cancer cells' ability to grow or multiply, but different groups of drugs harm cancer cells in different ways.

Chemotherapy can be given in different ways depending on the specific drug. See **Methods to Administer Drugs** on page 9 to learn more. Chemotherapy may also be combined with radiation therapy, targeted therapy, immunotherapy or stem cell transplantation.

Chemotherapy can also damage healthy cells and cause side effects. Side effects of chemotherapy can include appetite changes, nausea and vomiting, diarrhea, constipation, mouth sores, hair loss, anemia, skin changes, fertility issues, and problems with concentration and focus. Ask members of the healthcare team what to expect and alert them to any new or worsening symptoms.

Caregiver Responsibilities During Chemotherapy. During chemotherapy, there are many things you can do to help your loved one. Side effects may make it more difficult for your loved one to carry out many daily tasks, such as

cleaning, cooking, or grocery shopping. You can take on these tasks and assist with treatment adherence and side-effect management. Your loved one may also need you to accompany them to medical appointments.

Your loved one may receive chemotherapy at a treatment center or follow an oral therapy regimen at home. Turn to ***Drug Therapy at a Treatment Center*** and ***Drug Therapy at Home*** starting on page 11 to learn how you can assist your loved one and questions to ask the healthcare team.

If your loved one has a device in place to administer chemotherapy drugs, you can assist your loved one in caring for the device and checking for signs of infection. Turn to ***Caring for a Central Line, PICC Line or Port*** on page 10 to learn more.

Targeted Therapy. Targeted therapy is another type of drug therapy used to treat cancer. Unlike the drugs used in chemotherapy, the drugs used in targeted therapy specifically attack cancer cells. They “target” the genetic changes or proteins that contribute to the cancer cells’ growth and survival.

Each cell in the body has chromosomes that carry genes. Genes give instructions for making proteins. Proteins help the cell to do its job. Changes to chromosomes or genes cause normal cells to become cancer cells. Cancer cells do not function properly, but they continue to grow and divide.

Not all blood cancer cells are the same so a targeted therapy that may be appropriate for one patient may not be appropriate for another patient. The specific genetic or molecular markers that the drug targets need to be present in the cancer cells for the drug to work. The healthcare team will do tests to identify these genetic or molecular markers.

Some examples of tests used to identify the “targets” of targeted therapy include cytogenetic analysis, which examines the chromosomes of the cancer cells, and fluorescence in situ hybridization (FISH), which is used to look at the genes or chromosomes in cells and tissues. Doctors use these tests to find cancerous changes in chromosomes and genes.

Targeted therapies may cause side effects, but they may be different or less severe than the side effects caused by chemotherapy. Usually, the drugs used in targeted therapies do not affect healthy cells as much as standard chemotherapy drugs. The types of side effects vary depending on the specific drug used. Rashes are a common side effect of targeted therapies. The patient may also experience nausea, fatigue, diarrhea, fever, muscle or joint pain, or other side effects. Ask members of the healthcare team what to expect and alert the healthcare team to any new signs and/or symptoms or side effects.

Targeted therapies may be used along with chemotherapy or other treatments. Targeted therapy drugs can be administered in a variety of ways. See ***Methods to Administer Drugs*** on page 9 to learn more.

Caregiver Responsibilities During Targeted Therapy. Depending on the specific treatment, your loved one may experience side effects that can make it more difficult to carry out daily tasks, such as cleaning, cooking, or grocery shopping. You can help with these tasks and assist with treatment adherence and side-effect management.

Your loved one may receive targeted therapy at a treatment center or follow an oral therapy regimen at home. Turn to ***Drug Therapy at a Treatment Center*** and ***Drug Therapy at Home*** starting on page 11 to learn how you can assist your loved one and questions to ask the healthcare team.

If your loved one has a device used to administer drugs in place, you can assist your loved one in caring for the device and checking for signs and/or symptoms of infection. Turn to ***Caring for a Central Line, PICC Line or Port*** on page 10 to learn more.

Immunotherapy. Immunotherapy, also called “biological therapy,” utilizes the patient’s own immune system to fight cancer. The body’s immune system helps protect against disease and infection. In most circumstances, the body’s natural immune system seems unable to identify cancer as a foreign invader. Immunotherapy is based on the concept that immune cells or antibodies that can recognize and kill cancer cells can be produced in the laboratory and then given to patients to treat cancer. Several types of immunotherapy are either approved for use by the United States Food and Drug Administration (FDA) or are under study in clinical trials to determine their effectiveness in treating various types of cancer.

Immunotherapy treatments and the ways in which the treatments are given vary. So do side effects. Common side effects of immunotherapy include skin reactions (rashes) and flulike symptoms, such as fatigue, body aches, nausea, and fever. However, other side effects are possible. Ask members of the healthcare team what to expect and alert the healthcare team to any new signs, symptoms and/or side effects.

Chimeric Antigen Receptor (CAR) T-Cell Therapy. Chimeric antigen receptor (CAR) T-cell therapy is a type of immunotherapy that uses a person's own immune cells (T cells) to identify and attack cancer cells. In CAR T-cell therapy, T cells are taken from a patient's blood and sent to a laboratory. There, technologies are used to change the genetic makeup of cells. These genetically modified T cells will express a specific receptor (the chimeric antigen receptor) that allows them to identify and attack cells that have the target antigen. In the laboratory, the number of these engineered T cells is multiplied and the modified cells are eventually returned to the patient and re-infused into the bloodstream.

Most side effects associated with CAR T-cell therapy can be managed with supportive care and medication. However, serious side effects are associated with CAR T-cell therapy, some of which can be life threatening. Diligent monitoring of a patient's condition after CAR T-cell infusion is critical to minimize the risk of serious side effects.



Visit www.LLS.org/booklets to view **Chimeric Antigen Receptor (CAR) T-Cell Therapy**.

Caregiver Responsibilities During Immunotherapy. Depending on the specific treatment and side effects, your loved one may or may not need assistance with everyday tasks. Even so, cancer treatment can be mentally and physically draining, so they may need emotional support or help with shopping, cooking, or cleaning. If your loved one does experience side effects, you can help your loved one to manage them. You can also accompany your loved one to appointments and assist with treatment adherence.

Radiation Therapy. Radiation therapy, also known as “radiotherapy,” uses high-energy x-rays or other types of radiation to kill cancer cells. Although the radiation is directed at cancer cells, it can also damage healthy cells, but current methods minimize the damage done to nearby tissues.

When radiation therapy is used for blood cancer treatment, it's usually part of a treatment plan that includes drug therapy. Radiation therapy is sometimes given to prepare a patient for a stem cell transplantation. It can also be used to relieve bone pain and pain or discomfort caused by an enlarged liver, lymph node(s) or spleen.

External Beam Radiation. External beam radiation is the type of radiation therapy used most often to treat blood cancers. A focused radiation beam is delivered from outside the body by a machine. During the radiation treatments, the patient will lie on a table in the same position every time. A member of the healthcare team may mark the patient's skin with small dots of semi-permanent ink to ensure that the radiation is aimed at the same part of the body during each treatment session. Receiving treatment is similar to having an x-ray, but the radiation is stronger.

Treatments are typically done every weekday for a period of 2 to 4 weeks. The appointments are usually quick. The patient will likely spend 20 to 30 minutes in the treatment area. Even though actual radiation exposure only lasts a few minutes, setup can take longer.

Proton Beam Radiation. At some cancer centers, proton beam radiation may be an option. This type of radiation uses proton beams instead of photon beams (x-rays). Protons are particles with a positive charge. Proton beam radiation can be more targeted than photon beam radiation. This helps to minimize damage to healthy tissues and organs and may decrease the risk of long-term and late effects. This type of radiation therapy is newer and requires a special machine.

Caregiver Responsibilities During Radiation. You can help by going with your loved one to these daily treatments or by coordinating schedules with family members and friends who are available to accompany your loved one if they don't want to go alone. However, the person who goes with your loved one will not be allowed in the room while the actual radiation treatment takes place.

Typically, radiation causes fewer side effects than chemotherapy; however, fatigue is a common problem for patients undergoing radiation therapy. Your loved one may need some assistance with daily tasks in order to rest.

You may also need to help your loved one with skin care. Radiation can cause the skin to become red and irritated and occasionally it will blister (similar in some ways to a sunburn). Your loved one should bathe the area with warm water, protect the area from the sun, and wear loose clothing. Do not use skincare products on the area without first checking with a member of the healthcare team.

If your loved one receives external beam radiation, you and other people in contact with your loved one will not be exposed to any radiation.

Stem Cell Transplantation. Stem cell transplantation, sometimes referred to as “bone marrow transplantation,” is a procedure that replaces unhealthy blood-forming cells with healthy cells.

First, the patient receives a regimen of high-dose chemotherapy and/or radiation therapy which kills the patient’s stem cells to increase the chance of eliminating the blood cancer in the marrow. This is called “pretreatment” or “conditioning treatment.” See **Chemotherapy** on page 3 and **Radiation Therapy** on page 5.

After the conditioning treatment, the patient receives the stem cell transplant. Stem cells are transfused into the patient’s blood. The transfusion is done through a catheter and can last several hours. The transplanted stem cells go from the patient’s bloodstream to their marrow. The new cells grow and provide a supply of red blood cells, white blood cells (including immune cells) and platelets.

Types of Stem Cell Transplantation. There are four types of stem cell transplantation. The three most common are:

- Autologous transplantation: The stem cells come from the patient’s own body, before they receive conditioning treatment.
- Allogeneic transplantation: The stem cells come from a healthy person (the donor).
- Reduced-intensity stem cell transplantation: As in an allogeneic transplant, the stem cells come from a healthy person (the donor), but the conditioning chemotherapy is less intensive.

A fourth type of stem cell transplantation, syngeneic transplantation, is an option for patients who have an identical twin with whom the patient has identical genetic makeup and tissue type.

Finding a Donor. For an allogeneic stem cell transplant, the patient will need a bone marrow donor. To determine if a potential donor is a match for a patient, a lab technician examines samples of tissue cells from each person to compare the proteins on the outer part of the cells. These proteins are called “human leukocyte antigens (HLAs).” If the HLAs on the donor cells are either identical or similar to that of the patient’s cells, the transplant is more likely to be successful.

In some cases, the donor is a sibling (if one is available) if they are a match for the patient. Otherwise, an unrelated person with stem cells that match the patient’s tissue type can be used. The healthcare team can find matched unrelated donors (MUDs) through stem cell donor banks or registries.

Other Sources of Donor Stem Cells

Haploidentical donor. A potential stem cell donor who has a 50 percent HLA match with a patient is referred to as a “haploidentical donor.” Sometimes it is not possible to find a donor who is a close HLA match with the patient. Siblings have a 50 percent chance of being haploidentical. If the discrepancy in tissue type is not too great and the benefits of treatment outweigh the risk, a transplant may still be a possible option for a person with a haploidentical donor.

Cord blood. Stem cells are present in blood from the placenta and umbilical cord of a newborn baby. These stem cells can repopulate the marrow of a compatible recipient and produce blood cells. Frozen cord blood is a source of donor stem cells for transplantation to HLA-matched recipients. Most cord-blood transplants are given by either matched or nearly matched unrelated donors.



For more information about stem cell transplantation, visit www.LLS.org/booklets to view ***Blood and Marrow Stem Cell Transplantation***.

The National Bone Marrow Transplant Link ([nbmtlink](http://nbmtlink.org)) helps patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services. Visit www.nbmtlink.org or call **(800) LINK-BMT [(800) 546-5268]** for more.

Graft-Versus-Host Disease (GVHD). Graft-versus-host disease develops after an allogeneic transplantation when the donor's immune cells mistakenly attack the patient's normal cells. This reaction can be mild, moderate or severe—even life threatening. Its signs and/or symptoms can include:

- Rashes
- Blistering
- Nausea, vomiting, abdominal cramps, diarrhea and loss of appetite
- Jaundice (yellowing of the skin), which indicates liver damage
- Excessive dryness of the mouth and throat, leading to ulcers
- Dryness of the eyes, lungs, vagina and other surfaces

Graft-versus-host disease can be either acute or chronic. Its severity depends on the differences in tissue type between patient and donor. The older the patient, the more frequent and serious the reaction may be.

One to two days before the stem cell infusion, the healthcare team will give the patient a regimen of drugs to help prevent GVHD. These regimens suppress the immune system. The patient may need to continue to take these drugs for many months after transplantation. These drugs, in addition to early detection and advances in understanding the disease, have resulted in a significant reduction in serious or fatal outcomes from GVHD. However, GVHD doesn't always respond to these treatments. It can still have a fatal outcome. Many deaths related to GVHD occur because of infections that develop in patients who have suppressed immune systems.

Caregiver Responsibilities During a Stem Cell Transplant. During the pretreatment (conditioning) chemotherapy and/or radiation treatment, the caregiver can assist the patient with daily tasks, help the patient manage side effects, and accompany the patient to treatment.

After the stem cell transplant, the patient may spend 30 or more days in the hospital. Once the patient leaves the hospital, the caregiver can help the patient reduce the risk of infection by cleaning the home, practicing good food safety, caring for pets, encouraging proper self-care and hygiene, and helping the patient to avoid crowds and people who are sick. The caregiver can also be on the lookout for signs and/or symptoms of GVHD and alert the healthcare team to any changes to the patient's well-being.

If your loved one lives more than 15 to 20 minutes from the treatment center, the healthcare team may require that you both find a place to stay that is closer to the center. This is important in case serious complications arise after your loved one is discharged from the hospital. Some treatment centers offer special housing for patients undergoing a stem cell transplant. However, cost can be an issue, so discuss options with your treatment team. During this time, the patient must have a caregiver with them. If the patient does not have caregiver available post-transplant, the healthcare team may opt not to do a transplant. Regardless of distance, even if the patient is 5 minutes from the hospital, they must have a caregiver.



Read the **Chemotherapy** and **Radiation Therapy** sections on pages 3 and 5 to learn more about each of these treatments.



For more information about GVHD, visit www.LLS.org/booklets to view **Graft-Versus-Host Disease**. Visit www.joeshouse.org for a searchable database of discounted lodging facilities near treatment centers, such as hospitality houses and hotels that offer medical rates.

Clinical Trials. Taking part in a clinical trial is a treatment option that many blood cancer patients will consider at some point in their journey. A clinical trial may be the best treatment choice for some blood cancer patients. There are trials for:

- Patients who are receiving their first treatment
- Patients whose first treatment was not effective
- Patients whose cancer has returned following a period of remission
- Patients whose disease is in remission (for these patients, the goal is to extend remission).
- Patients who have not been able to achieve remission

FACT

Advances in treatment for blood cancers depend on patients' participation in clinical trials.

How Do Clinical Trials Work? A cancer clinical trial is a controlled research study conducted by doctors to test a new treatment, new combinations of treatments, or new dosages. A treatment that's proven safe and effective in a cancer clinical trial may be approved by the FDA for use as a standard treatment. Virtually all of today's standard treatments for cancer are based on the outcomes of previous clinical trials.

The purpose of blood cancer clinical trials is to improve treatment options by:

- Increasing survival
- Decreasing the side effects of treatment

Who Can Participate? Each clinical trial has a "road map" or protocol that includes information about which patients are eligible to enroll in the trial and which will be excluded from participation. These inclusion and exclusion criteria are very specific and usually cannot be changed.

Eligibility for any given clinical trial depends on many factors, such as:

- Diagnosis
- Stage of the disease
- The patient's current physical condition
- Other medical problems
- Prior treatments and responses to those treatments
- Presence or absence of certain genetic mutations
- Age

Clinical trials are carefully designed studies that put the health and safety of the patients first. Placebos are not used in cancer clinical trials unless they are given along with an active drug. No one can be forced to take part in a study. Participation in a clinical trial is always voluntary, and patients can leave the study at any time.

What Should You Do if Your Loved One is Interested in a Clinical Trial? Ask the healthcare team if a clinical trial could be considered at this particular point in the patient's treatment. Clinical trials may be considered in many situations including, but not limited to:

- Newly diagnosed patients considering a first treatment
- Patients whose first or subsequent treatment was not effective
- Patients whose disease has come back after a period of remission
- Patients whose current treatment is causing unacceptable side effects
- Patients who desire an alternative to the suggested treatment
- A patient whose disease is in remission and who is interested in possible ways to extend remission

The patient does not have to wait until the disease is in an advanced state to participate in a clinical trial.

Some of the many things a patient needs to consider before they decide to enter a clinical trial, include:

- The potential side effects of the treatment
- Required tests and procedures
- The number of doctor visits
- The amount of time the patient may be required to be away from home
- Potential costs involved and which costs are covered by the clinical-trial sponsor, which are covered by the patient and which are covered by the insurance company



Talk to an LLS Information Specialist to learn more. Call **(800) 955-4572** or visit www.LLS.org/InformationSpecialists. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical-trial process. Visit www.LLS.org/CTSC for more information.



For more information about clinical trials, visit www.LLS.org/ClinicalTrials or visit www.LLS.org/booklets to view ***Understanding Clinical Trials for Blood Cancers***.

Methods to Administer Drugs. The drugs used in chemotherapy, targeted therapy and other treatment regimens can be given in different ways depending on the specific drug. Commonly used methods of administration include:

- Intravenous (IV)—into a vein
- Oral (PO)—by mouth as a pill, liquid or capsule
- Intramuscular (IM)—injection into a muscle
- Subcutaneous (SC)—injection under the skin
- Intrathecal—into the cerebrospinal fluid (CSF)

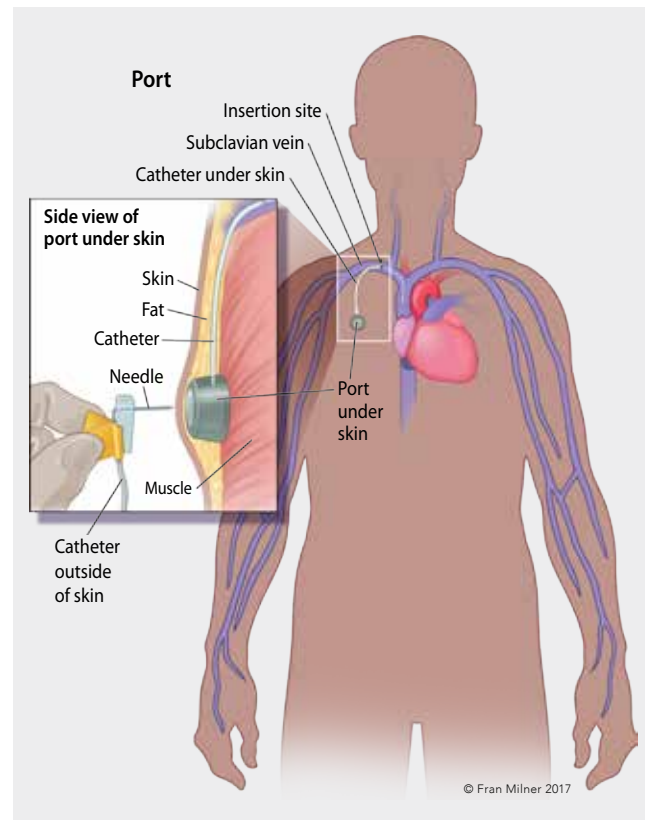
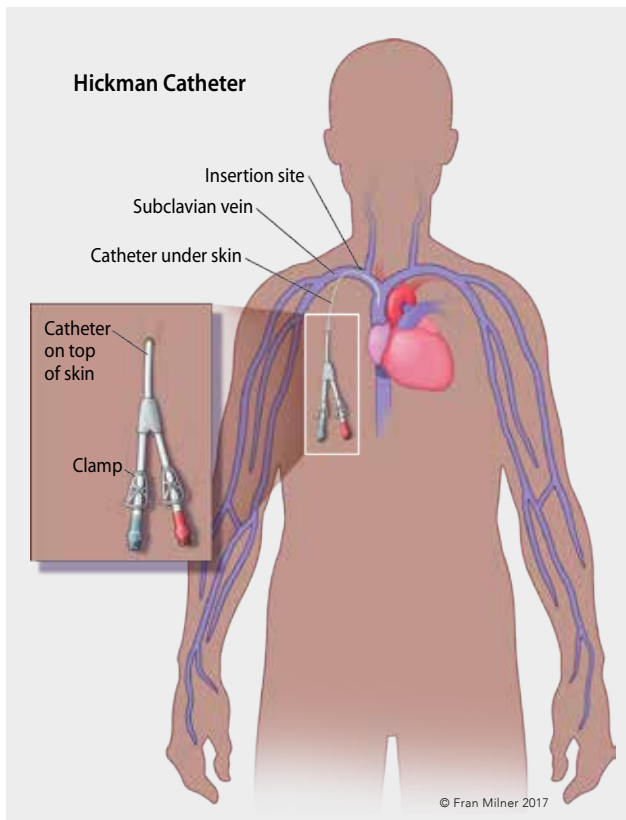
How Patients Receive IV Treatment. Certain medications irritate the veins and make repeated IV placement difficult. Many patients find that chemotherapy drugs can be given more conveniently and comfortably through a line or central venous catheter that can stay in place longer than a regular IV catheter.

- Central line: A thin tube that is put under the skin and threaded into a large vein in the chest or neck. A central line is placed by a doctor. The central line stays firmly in place. It can remain in place for weeks or months. A central line also allows for safe and painless blood draws for lab work. Central lines are also called “central venous catheters (CVCs).” See the image of a **Hickman® catheter** on page 10.

- Port: This is a small device attached to a central line. The port is surgically placed, typically under the skin of the chest. After the site heals, no dressings are necessary, and no special home care is needed. To access the vein, the nurse inserts a needle through the skin into the port. A numbing cream can be put on the skin before the port is used. See an image of a port below.
- Percutaneously (under the skin) inserted central venous catheter (PICC line): This type of central line is typically inserted through the skin and into a vein in the arm. The doctor or nurse uses a guide wire to thread the PICC line through the vein until it reaches the superior vena cava, a large vein above the heart. Once the PICC line is placed, blood for lab work can be safely and painlessly withdrawn from a capped, self-sealing valve at the end of the catheter.

These devices can be used to administer chemotherapy drugs, other medications, blood products, fluids or nutrition. They can also be used to take blood samples for lab tests.

After the device is in place, the healthcare team will explain how to clean and care for the central line. Talk to the healthcare team about the best way for your loved one to receive treatment.



Hickman® Catheter: An example of a type of central line.

Port: A port used with a central line.

Caring for a Central Line, PICC Line or Port. Since these devices can sometimes stay in place for months, you and your loved one will need to know how to care for the device at home.

If your loved one has a central line, PICC line, or port, the site will need to be cleaned and monitored for infection or other issues such as the development of blood clots (thromboses). Hospital or clinic staff will show you and your loved one how to clean and care for the device. Signs and/or symptoms of infection include:

- Redness
- Pus and other drainage

- Warmth to the touch
- Bad smell
- Increased pain
- Fever

Let the healthcare team know immediately if you notice these signs and/or symptoms. Although blood clots often have no symptoms, some signs and/or symptoms of a blood clot can include pain, redness, and discoloration of the skin. An ache in the shoulder or jaw could also be a symptom of a blood clot. Talk to the healthcare team about your loved one's risk for blood clots and what to do in an emergency situation.

Any long-term device will also need to be flushed periodically. The healthcare team will provide a plan for how to flush the device, as well as how often this must be done.

Additional Care and Use of Devices. Depending on your loved one's specific treatment plan and needs, it's possible that you, as the caregiver, will also need to learn how to use the device when you administer drugs, fluids or nutrition at home. This may include:

- Learning how to connect and disconnect the lines
- Programming a "pump" to deliver medications or fluids as prescribed
- Flushing the lines
- Checking for air bubbles in the line or other issues
- Storing and disposing of medical items properly
- Maintaining a sterile environment to prevent infection
- Watching for signs of infection such as discharge, redness, swelling or pain around the insertion site

If your loved one's care involves the use of a device, a member of the healthcare team will teach you how to use and care for the device. In this type of situation, you and your loved one will likely receive scheduled at-home visits from a nurse who will draw blood for the lab tests and oversee the care of the line, as well as the administration of drugs, fluids, and/or nutrition.

Drug Therapy at a Treatment Center. If the drug therapy is administered by an IV infusion either at the hospital or at a treatment center, you can keep your loved one company during these appointments. Infusions can last for several hours; some even require hospitalization.

Questions to Ask Members of the Healthcare Team

Before the patient begins **treatment at a clinic or treatment center**, ask the healthcare team the following questions:

- Is there anything the patient needs to do to prepare for infusions?
- What signs and/or symptoms require medical attention, and what should I do if I notice these signs and/or symptoms?
- Whom can I call after hours or in an emergency situation?
- Are there any foods, vitamins, medications, or supplements that the patient needs to avoid because they can interact with the drug after infusions?
- Are there any precautions I need to take when helping the patient once they come home after an infusion?

Drug Therapy at Home. Treating cancer at home has many advantages. Your loved one can be comfortable at home and avoid additional trips to the treatment center. However, when treating cancer at home, there’s a shift in responsibility from the healthcare provider to the patient (and caregiver). “Treatment adherence” means taking medication as prescribed. Treatment adherence is very important. The medication may not work effectively if the patient does not take it as prescribed by the doctor. You can assist your loved one with taking the medication as prescribed.

In some cases, your loved one may need to receive medications by an IV infusion at home. See **Additional Care and Use of Devices** on page 11 to learn more.

Questions to Ask Members of the Healthcare Team

Before the patient begins **treatment at home**, ask the healthcare team the following questions:

- What if the patient misses a dose?
- What if the patient vomits immediately after taking the medication?
- Are there any foods, vitamins, supplements, or medications that the patient needs to avoid because they can interact with the drug?
- Is it safe for the patient to drink alcohol while they are taking this drug?
- When should the patient take the medication and how often?
- How should the medication be stored and handled?
- Is it safe for me to handle the medication?
- Does the patient need to take this drug with food?
- When and how should I contact the healthcare team with questions?
- How do I contact a member of the healthcare team after hours?

Your Loved One’s Treatment Plan. Once the treatment plan is in place, write down the details of your loved one’s treatment plan in the space below and on the following notes pages. Keep in mind that the treatment plan may change, depending on how your loved one responds to treatment.

Questions to Ask Members of the Healthcare Team

- What does the treatment plan include?
- How will the treatment be administered?
- Will the patient be treated in the hospital or at an outpatient treatment center?
- How long will the treatment last?
- Does a caregiver need to be with the patient while the treatment is administered?
- What are the side effects and long-term effects of this treatment?
- Can the patient be referred to a palliative (supportive) care specialist to get help with managing side effects?
- What signs and/or symptoms indicate I should call the healthcare team? Whom can I contact after working hours if I have questions or concerns?
- What signs and/or symptoms indicate that a trip to the emergency room is necessary?
- Will the patient need to follow a special diet or avoid any specific foods, medications or supplements while receiving this treatment?
- Are there any other precautions that need to be taken, by either the patient or myself, while the patient is receiving this treatment?
- What kind of testing will be done to monitor the disease and treatment? How often will the testing be needed?
- How will we know if the treatment is effective? What options are available if the treatment is not effective?

